Patients nearing death may experience a phenomenon known as the Kennedy Terminal Ulcer (KTU). The skin breakdown in the sacral/coccygeal area was first noted by Karen Lou Kennedy and other healthcare workers at the Byron Health Center, an intermediate care facility in Fort Wayne, IN, in 1983. The ulcer occurred despite preventive measures. Skin deterioration progressed rapidly, even in the course of a single day. Caregivers and family members were surprised at the sudden onset. Byron staff noted this type of ulcer heralded impending death. This case study describes two extended care facility residents whose skin changes in general, and the development of a KTU in particular, were associated with end of life.

**Literature Review**

The KTU is described as a pear-, butterfly-, horseshoe-, or sometimes irregular-shaped red/yellow/black ulcer, similar in appearance to an abrasion or blister, that may occur suddenly. The blister roof may be very fragile and even gentle cleansing may change the skin surface from intact to a fairly large open wound. The ulcer may darken quickly before demarcating within days; it has the characteristics of early deep tissue injury and can progress rapidly to a Stage II, Stage III, or Stage IV ulcer (see Figure 1). Sometimes the surrounding tissue is soft or loose beneath the surface. Time is a key factor. Pressure ulcers in general can develop within 24 hours of skin insult and take as long as 5 days to present. According to Kennedy and others, KTUs come on quickly and progress rapidly, often within hours.

Initially, the KTU was thought to be located exclusively in the sacral/coccygeal area; this was later amended to be described as its usual location. KTUs have been known to appear on the heels, posterior calf muscles, arms, and elbows. Early descriptions compare the look of the buttocks in some cases to being dragged over a black-topped road.

The ulcer also is addressed in literature on providing evidence-based treatment options for patients needing palliative or end-of-life care. The primary care provider or

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**Abstract**

The Kennedy Terminal Ulcer (KTU) is an unavoidable skin breakdown or skin failure that occurs as part of the dying process. Research is limited but the literature suggests that KTUs are typically pear-shaped, red/yellow/black, similar in appearance to an abrasion, and tend to occur suddenly in the sacral/coccygeal region not long before death. In this case study, one resident of a long-term care facility suddenly developed a full-thickness ulcer. The ulcer did not respond to treatment and the resident died 6 weeks following ulcer development. Another resident, admitted with a full-thickness ulcer, also did not respond to standard measures of care and general skin failure was observed. She died after 5 months. Research about end-of-life phenomena such as skin failure is needed to help clinicians, caregivers, and patients understand what is occurring and facilitate the provision of optimal and appropriate end-of-life care.

**Key Words:** pressure ulcer, end-of-life care, Kennedy Terminal Ulcer

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wound consultant customarily makes the diagnosis and prescribes/recommends treatment for this skin failure/KTU. These actions often are based on the recommendations or suggestions from the nurses working with the patient and his/her family.

A KTU has been found to be a pressure ulcer that heralds the end of life. Kennedy published results of a 5-year retrospective study of approximately 500 persons with pressure ulcers regarding pressure ulcer prevalence rate at her facility, finding that residents developing pressure ulcers died within 2 weeks to several months; 55.7% of people with pressure ulcers died within 6 weeks of onset. As part of their descriptive study comparing different methods of capturing and assessing prevalence and incidence data, Hanson et al noted that 62.5% of patients in hospice care developed pressure ulcers in their final 2 weeks of life. Theoretically, many of the pressure ulcers in these studies could be KTUs.

The skin is an organ that (similar to other organs) can fail, especially as people age. Skin integrity is dependent on the function of all other organ systems for nutrition, circulation, and immune function. Raised temperature, decline in circulation, pressure, and other yet-to-be determined causes increase tissue demands on the skin and can have an impact on skin integrity; pressure ulcers, a type of skin death, frequently occur in persons with a heavy disease burden, especially those at or near the end of life. Although the skin is approximately 10% to 15% of total body weight, it is known to require 25% to 33% of cardiac output. It is no surprise then that the skin in patients on vasopressors that divert blood to major organs for survival is compromised.

Langemo and Brown describe skin failure as “an event in which the skin and underlying tissue die due to hypoperfusion that occurs concurrent with severe dysfunction or failure of other organ systems.” Unlike other failing organs, skin changes are visible. Thomas noted that clinicians focus on the environment to effect change for patients with pressure ulcers, as well as on the role of risk factors in wound healing; however, he theorizes wounds may be more affected by intrinsic factors than is realized. Citing data in Jones and Fennie’s multisite retrospective chart review of pressure ulcer treatment in various settings during a period of more than 6 months, Thomas concluded that despite prudent management of extrinsic factors such as pressure offloading and nutrition, intrinsic factors may have a stronger influence on the ability to heal wounds.

The section concerning pressure ulcers in the 2008 American Medical Directors Association (AMDA) Guidelines, developed by an interdisciplinary group of clinicians, refers to the KTU as an unavoidable ulcer. When research was limited, a consensus approach was implemented utilizing clinician expertise to establish recommendations. The recommendation regarding KTU is also reflected in the National Pressure Ulcer Advisory Panel’s (NPUAP) update of the pressure ulcer staging system. Suspected deep tissue injury is an additional stage denoting full-thickness injury.

The federal government requires completion of the Minimum Data Set (MDS), an assessment form used for all residents in long-term care facilities certified by Medicare or Medicaid. Presently, suspected deep tissue injury is not included in this document. Thus, if the skin is intact when the KTU is first noted, it would be designated as a Stage 1 on the MDS. Eschar-covered areas would be noted as a Stage 4. Further description of the ulcer may be addressed in the healthcare provider’s note.

Pressure ulcer care and documentation seem to be subject to increasing regulatory and legal scrutiny. Hogue, in addressing increased litigation risk for clinicians specializing in wound care, noted that wound development in patients often is viewed as negligence; earlier perspectives seemed to accept that wounds could develop despite appropriate intervention. As an analogy, if a cardiologist provides appropriate care and the patient suffers a myocardial infarction, usually no fault may be found. If a wound care clinician provides and documents appropriate care and the patient’s skin fails, the same standards should apply. Thus, determining that an end-of-life occurrence was inevitable due to organ failure has legal and reimbursement, as well as clinical, ramifications.

Skin Changes at Life’s End (SCALE). In April 2008, Gaymar Industries, Inc (Orchard Park, NY) provided an unrestricted educational grant for a consensus meeting to discuss skin changes at the end of life, including the KTU. The panel of wound and skin experts recognized pressure ulcer development occurred not only in terminal patients, but also among patients experiencing overwhelming illness, lending credence to the relationship between general organ failure and skin failure. Panel members also agreed these pressure ulcers were unavoidable.

This end-of-life, skin care and patient care initiative resulted in 10 statements relevant to end-of-life wound care. These statements address assessment, accurate description
and documentation of skin/wound abnormalities, using etiology to guide care goals (ie, prevention, treatment, avoiding further deterioration, and palliation), realistic expectations, communication, identification of risk factors (eg, limited mobility, compromised nutrition, decreased perfusion, incontinence), reduced tolerance of pressure on skin, manifestation of evidence of dying in skin, and education.

Case Study

**Case 1:** Ms. A, an otherwise healthy woman in her 80s diagnosed with progressive Alzheimer’s dementia, lived in a long-term care facility for several years. Preventive skin measures had been successfully in place since admission. Without warning, Ms. A developed a full-thickness sacral ulcer (see Figure 1). Horrified, staff quickly called for a wound consult. Because of the sudden onset and Ms. A’s clinical course, the ulcer was diagnosed when it appeared as a KTU.

Staff and state surveyors involved in a facility assessment at the time were eager to learn more about this phenomenon. Information was exchanged among all relevant parties that fostered clinical sharing and teaching that benefited everyone, including the resident: relevant persons were made aware that Ms. A’s condition was terminal despite the best of care, realistic outcomes were re-assessed, and compassionate palliative measures were implemented. Mrs. A’s wound continued to deteriorate despite appropriate care; she expired 6 weeks after ulcer development.

**Case 2:** Sixty-three year old Ms. B was terminally ill with multiple sclerosis that rendered her paralyzed and immobile. She presented with a full-thickness sacral pressure ulcer (see Figure 2). Despite intervention, the area continued to worsen. Information about the KTU was shared with Ms. B and her husband, helping them realize she was in the end stages of life. Husband and wife decided not to prolong her life with feeding tubes and other clinical options because of the effect of these measures on her quality of life. Hospice care was initiated. It was extremely difficult for everyone to observe skin changes associated with end of life; although staff continued with preventive measures, her skin kept failing. In her final days, when Ms. B did not want to be turned to one side, the staff honored her wishes, even though they had been able initially to cajole her into a turning schedule.

Ms. B’s determination to live shocked everyone. Initially, it was thought she would pass in a few days; 5 months elapsed before she died. She had lost a great deal of weight and was literally skin and bones; her skin had failed everywhere, even where there was no possibility of pressure. It was agonizing to care for her, watching her slowly slip away.

Discussion

Educating caregivers about the KTU often involves clinicians eager to share similar patient experiences, usually with a sense of relief and validation. Caregivers and family members often express that they knew they had done everything possible, but felt guilt and sometimes shame with the outcome. The realization of the inevitability of end-of-life events such as KTU, despite their best efforts, brought some to tears. Thus, information on the KTU is crucial. Knowledge affirms the ulcer occurs because the patient was nearing death, not from lack of care, and can help the patient and family navigate the clinical and personal choices that lie ahead. Rather than pursuing a course of healing, clinicians can institute a palliative approach, as well as ensuring that the patient, family, and all caregivers understand the terminal nature of the skin breakdown. These efforts should incorporate patient/staff/family education on the implications of end-of-life conditions, time to allow all interested individuals to understand and work through what may be devastating information, and switching to palliative care.
Conclusion

The diagnosis of KTU can be heart-wrenching for staff, families, and patients. Unlike managing other terminal conditions, KTU often is associated with an unfounded sense of guilt on the part of the clinician or family members relevant to preventive measures not taken, especially in a healthcare arena that has deemed so many forms of pressure ulcers preventable. Learning about the KTU may assist everyone involved with the realization that this occurs because the patient is nearing death, not lacking care. It is evidence that the body’s largest organ is failing along with other major systems. KTU can be interpreted as a visible sign — an explanation — of what is transpiring with the patient. Diagnosis should help/guide the patient and family, allowing them to accept the inevitable. This knowledge and resolve may provide some a needed opportunity to get their affairs in order.

Further study is needed to better understand the KTU. What specifically is the etiology? What determines patient susceptibility? What is the incidence/prevalence? What are the main risk factors for skin failure? Research in appropriate facilities is encouraged and may be facilitated using the SCALE recommendations to guide care.

Realizing a patient has a KTU has become an “Ah-ha!” moment that helps guide patient care. Acknowledgement of this wound type may have implications for public policy as well. As increasing numbers of people achieve longer lives, the KTU may proliferate, requiring better understanding of this and other end-of-life phenomena.

References